
The Duct

Bringing you news on PSC



PSC PARTNERS
SEEKING A CURE

research, education, and support

PSC Partners Seeking a Cure Foundation Winter 2012



Mayo Clinic Welcomes PSC Partners Seeking a Cure

We are pleased to announce the details of the *PSC Partners Seeking a Cure Eighth Annual Conference* for PSC patients and caregivers, to be held at Mayo Clinic in Rochester, Minnesota, the weekend of May 4 - May 6, 2012.

I'd like to thank Dr. Keith D. Lindor, Dr. Konstantinos N. Lazaridis and Dr. Jayant A. Talwalkar, our Mayo Clinic co-hosts, who have put together an agenda of exceptional speakers and topics. I'd also like to thank Sandi Pearlman, who as conference co-chair, continues to do an outstanding job of coordinating every aspect of the event.

Please read through this conference edition of our newsletter carefully. Hopefully, many of you will be able to join us in Rochester to participate in a unique opportunity to learn from experts about the most recent developments in PSC treatments and research. Equally valuable is the chance to get to know PSCers and caregivers who freely share their concerns, advice and compassion. When we are together, there is a palpable positive feeling of strength, hope and support for one another..

In putting together the weekend agenda, we try to implement attendee suggestions from last year's conference evaluations. We have therefore incorporated topics such as the MELD system, new topics such as sleep and chronic illness, living donor liver transplantation, Dr. Gores' cholangiocarcinoma protocol, understanding PSC medications, and the gluten free diet. This year we are fortunate to have

world experts and thought leaders presenting the various facets of PSC treatment and research. Following each presentation, there will be ample time for attendee questions.

If you are a PSCer, please think about volunteering to enroll in Dr. Lazaridis' PROGRESS project, an important research project studying the genetic predisposition to PSC. For further details, or to sign up for PROGRESS, click here: [Click here](#) to contact Erik Schlicht, call 507-284-4312 or email him at schlicht.erik@mayo.edu..

If you are arriving early, please look at the suggestions provided on our website for activities in Rochester, and consider attending the casual get together on Thursday evening. Be sure to join us for our pre-conference activities on Friday: the get acquainted brunch and the interactive session with Dr. Amit Sood, Director of Research for Mayo Clinic's Complementary and Alternative Medicine Program.

If you have any questions, feel free to write to me at contactus@pscpartners.org.

I'm looking forward to reconnecting with my old PSC friends, meeting the new attendees and welcoming our entire PSC Partners family. Every year, our conference attendance increases, and invariably the weekend experience becomes even more powerful for everyone involved. Our 2012 conference will be no exception!

Thanks to the special spirit of our group, I always return home from the conference with renewed optimism, exciting knowledge and supportive friends. Please try to join us in 2012!

Together in the fight, whatever it takes!

Ricky Safer
CEO

Could you be a 2012 Conference Sponsor?

We love our sponsors and recognize their gifts to help support the conference.

Premier Platinum Level Sponsorship (\$10,000)

Gold Level (\$5000)

Silver Level (\$2500)

Bronze Level (\$1000)

Consider pooling donations with friends to have a greater impact. It's all tax deductible.



2012 Conference Information

We're pleased to announce PSC Partners Seeking a Cure's eighth annual conference for PSCers and caregivers which will take place in Rochester, Minnesota May 4-6, 2012 in association with the Mayo Clinic. Thank you to Drs. Keith D. Lindor, Konstantinos N. Lazaridis and Jayant A. Talwalkar for their professional guidance.

CONFERENCE AGENDA

Please check out the 2012 conference agenda for details of the entire weekend. Please see page 14 or [click here](#) to see the full agenda.

NOTES:

TEEN PROGRAM: We have organized some special activities for the teen PSCers attending the conference. Once the teens register for the conference, we will send them an update.

GO GREEN! With the exception of the Friday morning brunch at the Rochester Art Center and the Friday afternoon pre-conference session (both within easy walking distance), all weekend activities will take place in the DoubleTree Hotel, so you will NOT need a car.

EARLY REGISTRATION IN ROCHESTER

There will be a PSC Partners table in the DoubleTree ballroom foyer from Thursday morning through Friday evening at 6 p.m. so that attendees can register early and pick up their information packets as soon as they arrive.

We hope that you'll consider arriving in Rochester by Thursday evening May 3rd to participate in our pre-conference activities on Friday. Last year, more than half of the conference attendees came early. They greatly appreciated the chance to get acquainted with the other participants and gain healthy living tips before the official start of the conference.

SUGGESTIONS FOR THURSDAY, MAY 3

DAY ACTIVITIES: If you plan to arrive in Rochester early, please check out the PSC Partners [Event Site](#) for visitor information and printable maps. We would like to suggest two unique opportunities:

There is a free tour of the Mayo Clinic campus (15 minute film and one hour walking tour), which is held weekdays at 10 a.m., beginning in the Judd Auditorium on the subway level of the Mayo Building.

There is also a free Mayo Clinic Art and Architecture Tour (one hour and fifteen minute walking tour of their excellent interior art exhibits). This tour is held weekdays at 1:30 p.m., beginning in the Judd Auditorium on the subway level of the Mayo Building. You also have the option of checking out an audio player at the Gonda Building Lobby Information Desk for a self-guided audio art tour.

EVENING ACTIVITIES: Please stop in and join us at Z Pizza in the University Shoppes, upper level, for an informal get together from 6-9 p.m., Thursday, May 3rd. Z Pizza is located in the skyway and is easily accessible from both conference hotels. Z Pizza offers a number of options including pizza, salads, sandwiches and gluten-free and vegan choices. Most menu items are under \$10. Also running from 6-9 p.m. is Rochester's Artwalk. Visit downtown Rochester businesses, studios and galleries for an evening of refreshments, entertainment, and one-on-one conversations with local studios and galleries.

PRE-CONFERENCE ACTIVITIES FRIDAY, MAY 4

GET ACQUAINTED BRUNCH from 10:30 a.m.-12:30 p.m. (fee \$10 per person): Please join us for an informal brunch at the [Rochester Art Center](#), a short five minute walk from the DoubleTree Hotel via the skyway. Please register for the brunch at the same time you complete your conference registration.

FRIDAY AFTERNOON INTERACTIVE SESSION from 1:30-4:00 p.m.: Worried and stressed about life with PSC? Be SMART about it and join us for an interactive session in Stress Management and Resiliency Training. Whether you're a PSCer or a caregiver, stress affects us all. But we don't have to just give in or let it take control. Join Dr. Amit Sood, Associate Professor of Medicine, Director of Research and Practice, Integrative Medicine, Associate Director, General Internal Medicine Research, for an interactive session to learn how to better manage the stressors that affect your day and your life.

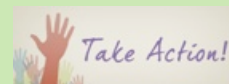
NEWCOMER ORIENTATION FOR FIRST TIME ATTENDEES from 5:30-6 p.m.: The goal of this short session is to give first time attendees a head start in understanding what you'll experience during the weekend and how to get the most out of the three days. To prepare for Saturday's sessions, we'll hand out a packet of reference materials with medical terms, abbreviations and acronyms that will provide the necessary background to better understand the medical presentations. We'll give you a background on PSC Partners Seeking a Cure foundation, our family-style culture, whom to ask for help, what to expect in each session and how to successfully navigate the jam-packed weekend.

**Consider
volunteering at the
conference!**

*It takes a lot to keep the
conference moving each day,
and we could use your help.*

*Check the box on the
registration form to let us
know that you will be
available behind the scenes
to make it a success!*

Thank you!



MENTOR/MENTEE CASUAL MEET AND GREET from 6-6:30 p.m. If you are a first time attendee (either a PSCer or a caregiver), when you fill out your registration form, we suggest that you request a mentor. We will match you with a mentor who will be in your same group during the weekend. You will have the opportunity to communicate with your mentor before the conference and have your questions answered. This session is your chance to be introduced in person to the mentor who has been helping you, and who will continue to be your special contact.

CONFERENCE FEES

Conference registration fee includes: Friday afternoon pre-conference sessions, Friday night reception dinner, Saturday breakfast, lunch, snack and banquet dinner, Sunday breakfast and snack, all presentations, breakouts, open forums and conference materials. The conference fee applies to ALL those who attend ANY PART of our conference and cannot be pro-rated.

Early Bird Fee:	From the opening of online registration until 2/10/12	\$160 per person
Standard Registration Fee:	2/11/12 to 4/5/12	\$170 per person
Late Registration Fee:	4/6/12 to 4/20/12	\$190 per person

ALL FEES MUST BE RECEIVED BY APRIL 20.

Friday pre-conference brunch: \$10 per person*

*The brunch fee is NOT included in the conference fee and will be added to your conference fees when you register.

Note: We try to keep our registration fees as low as possible, in the hope that more people will be able to attend the conference. PSC Partners and our 2012 conference sponsors subsidize a significant portion of your conference costs. (In 2011, the registration fee per person covered less than half the cost for each attendee; the rest was covered by our generous conference sponsors).

REGISTRATION INFORMATION

To register online, [click here](#).

CONFERENCE SPONSORS

Thank you to our 2012 conference sponsors:

Silver Level Sponsors: The Pearlman Family
 Ken and Patty Shepherd
 Jason and Jennifer Drasner
 Steve and Joanne Grieme
 Steve and Joanne Hatchett

Bronze Level Sponsors: Aubrey Goldstein and Caroline Vanneste

We are still in the process of looking for individual or corporate conference sponsors, so if you are interested in becoming a conference sponsor or if you know someone whom we should contact, please write to us at contactus@pscpartners.org.

IMPORTANT HOTEL INFORMATION

All conference events (starting Friday afternoon May 4th) will take place at the [DoubleTree Hotel](#) (150 So. Broadway). The DoubleTree is located just two blocks from the Mayo Clinic campus.

We are pleased to offer a discounted group rate for PSC Partners Seeking a Cure attendees both at the Doubletree Hotel (where the meeting will be held) for \$110 per night (plus state and local taxes) and also at the Hilton Garden Inn across the street for \$96 per night (plus state and local taxes). The group rate will be available until April 9 OR until the group block is sold out, whichever comes first. After April 9, the discounted group rate will only be offered depending on availability and prevailing rates, **so it is strongly advised that you make reservations as soon as possible to take advantage of the group rate.**

You may reserve your room

1. Online

- [Doubletree](#)
- [Hilton Garden Inn](#)

Or

2. By phone

- Doubletree: 507 281-8000
- Hilton Garden Inn: 507 285-1234

TRANSPORTATION INFORMATION

Click on the PSC Partners 2012 [Conference Event Site](#) to find detailed information on getting to Rochester (by car, train or plane), ground transportation from the Rochester and Minneapolis airports to the DoubleTree and the Hilton Garden Inn, parking options, etc.

We have negotiated a special rate of \$22.50 each way per person for shuttle service between the Minneapolis-St. Paul airport and the DoubleTree or the Hilton Garden Inn through [Go Rochester Direct](#). You must make roundtrip reservations in advance for the van in order to be assured a seat. Also, please be aware that it is an hour and a half drive from the Minneapolis airport to your Rochester hotel.

MISCELLANEOUS INFORMATION

PARTICIPATE IN PSC RESEARCH WHILE YOU ARE IN ROCHESTER: Here's your chance to make a real contribution to PSC research and help us all take a big step closer to unraveling the mysteries behind the disease. During the conference weekend, our co-host, Dr. Konstantinos Lazaridis, will be enrolling PSC patients in the important PROGRESS (PSC Resource of Genetic Risk, Environment and Synergy Studies) research project. This project is studying the genetic predisposition to PSC. For further details or to sign up for PROGRESS, [click here](#) or contact Erik Schlicht at 507 284-4312, schlicht.erik@mayo.edu.

As we get closer to the conference, time slots will be publicized for volunteers wanting to participate in the blood draw for PROGRESS. Blood draws will take place at the DoubleTree Hotel. It is recommended that you enroll in the study prior to arrival in Rochester. Please consider volunteering and helping us get one step closer to a cure!



Early Bird Conference Rates Will Expire on These Dates

February 10, 2012: End of early bird rates

Register for the conference before the late fees apply!

April 5, 2012: Register for the conference at the standard rate on or before April 5, when late registration starts.

HELP US FIND A CURE FOR PSC: Please consider donating to or holding a fundraiser for our Itching for a Cure/Road to Research campaign, as all donations go directly to support PSC research. For information, [click here](#).

PSC PARTNERS MAILING LIST: If you aren't already on our mailing list, please sign up now on our website homepage (www.pscpartners.org) to receive e-mail updates about the conference and other programs.

ANSWERS TO YOUR QUESTIONS:

2012 PSC PARTNERS CONFERENCE EVENT SITE: The Rochester Convention and Visitors Bureau has created a wonderful event site for our conference. [Click here](#) to learn about transportation options from the Minneapolis and Rochester airports to the DoubleTree and Hilton Garden Inn hotels, free tours at the Mayo Clinic, parking options in Rochester, Rochester dining, shopping and arts guides, and printable maps of Rochester, the Mayo Clinic, and the skyway and subway routes.



If you are a first-timer at the conference, make sure to sign up for a mentor when you register. A warm welcome will await you!

CONFERENCE FAQs: If you are attending your first PSC Partners conference, be sure to visit the [FAQ section on our website](#).

PHOTOS AT THE CONFERENCE: Informal photographs and videos will be taken throughout the conference weekend. If you object to the use of your likeness in these images for our website or promotional materials, please contact Meegan Carey at Meegan@pscpartners.org at any time.

CONFERENCE FLYER: Please print copies and deliver the flyers to your gastroenterologist or hepatologist to display in his/her office. See page 18 for more details.

COMMENTS FROM PAST ATTENDEES: If this will be your first PSC Partners conference, please take the time to read comments from some of our past attendees.

To read “I Refuse to Miss One of These Gatherings,” [click here](#).

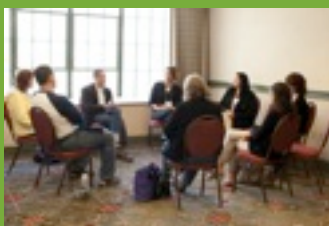
To read “The Top Ten Reasons to Attend a PSC Partners Conference,” [click here](#).

VISITOR INFORMATION

For visitor information on dining, activities or parking in Rochester, please [click here](#).

Thank you for your interest in the eighth annual PSC Partners Seeking a Cure conference. It will be an informative and fun weekend filled with new insights, caring friends and a sense of hope.

If you need further information or have any questions, please write to Ricky or Meegan at contactus@pscpartners.org or Sandi@pscpartners.org



We come from all over the U.S. and different corners of the world. Join us at the conference, wherever you are!

Sandi's Corner



Three Cheers for PSC Partners Conferences!

by Sandi Pearlman

Did you ever watch that old TV show, “Cheers,” the one with Sam and Diane, Carla, Cliff and Norm? It’s about a bunch of people whose lives revolve around a bar...at least on the surface. Okay. I know, I know, you’re already thinking I’ve flipped my lid writing about a TV show based on a bar in a PSC newsletter of all places, but bear with me for a second.

Because, you see, while Cheers was, in fact, about a group of (perhaps) high-functioning alcoholics and those who waited on them, it was also about a family, people who loved each other and really got each other even when the outside world didn’t play fair. It also happens to have a phenomenal theme song* and every single year as the PSC conference rolls closer and closer, it pops into my head. Now, it could be that I’ve spent too much time with insomnia and Nick-at-Nite (we’ll just pretend for the sake of this article that I’m not actually old enough to have seen them when they originally aired), but I think it’s more than that.

You see, in the real world, I’m the other. I need a transplant. I have a rare disease. I itch. I’m swollen. I can’t sleep and my brain occasionally forgets helpful things like where I am or what I’ve been doing or the word for “cat.” But at the conference, none of that matters. I’m not the other. I’m one and the same in the best of all possible ways. And you know what, you will be, too.

In a world where everyone is constantly judging everyone else, the conference is this lovely oasis in the storm. It’s Happy Hour, if you’ll pardon the drinking pun. You can scratch, need daytime naps, forget your words and even pass out (although we’d much prefer you conscious) and nobody will judge you. If you happen to be having one of those days where you scratch until you bleed, you won’t find judgment or even pity at a PSCP conference. Instead, you’re much more likely to find the person next to you offering up a tissue and commiserating about how awful it is to feel like fireants have taken up residence just under your skin. One look at a conference agenda will tell you that PSC is no laughing matter. Our topics range the scope from genetics to MELD, CCA to Urso, Transplant and Depression and back and forth and

everywhere in between. But lest you feel as though the conference is just about the tough and cold, hard facts of having an incurable illness, let me let you in on another little secret. PSC Partners conferences are also notorious for their laughter and fun.

My little sister--now not so little at 34, I realize--refers to the conferences as the best time she has all year. Another PSCer I know calls them her family reunions--with family she actually wants to see. And yet another PSCer has actually told his transplant team that they'd better make sure he's either transplanted before or after the conference because he's absolutely not missing one. The reason PSCP conferences inspire such loyalty and reverence is simple. Everyone is welcome, wanted and accepted. There's no need to pretend to be a 'healthy' person and try to take a bite of something when you're too nauseous to eat or to try and pretend anything else for that matter. You're in a room where everyone is gathered together for the same thing, to become better informed about this disease that has brought us all to this place in time and to find a way to defeat it. We're not powerless. We're powerful. We don't need liquid courage or fortifying. We're enough. No matter how weak we sometimes feel in regular life, here, together, we're strong.

This year, I'm the co-chair for the conference. I can tell you firsthand that the speakers we have lined up are truly phenomenal and to say that they're widely regarded as some of, if not the, best in their fields is not an overstatement. But you know what matters just as much to me, they care. Not one of the 'demigods' of PSC has had even the tiniest bit of an ego. In fact, just the opposite. They've been gracious and questioning and really want to work with PSC Partners to give all of us the answers we need and to address the subjects that we most care about. For many PSCers, names like Lindor and Gores, Lazaridis, Kane and Talwalkar are just those words behind authors' bylines of numerous medical articles. For me, and I know for all of you attending, they're about to become so much more. They'll no longer be nameless, faceless doctors working out in space somewhere. No, they'll be the ones seated next to you, holding your hand, Cliff to your Norm or Sam to your Diane. They'll be your Cheers-ing section and you'll certainly be glad you came.

**Making your way in the world today takes everything you've got.
Taking a break from all your worries, sure would help a lot.
Wouldn't you like to get away?
Sometimes you want to go
Where everybody knows your name,
and they're always glad you came.
You wanna be where you can see,
our troubles are all the same
You wanna be where everybody knows
Your name.*

**To see PSC Partners Conference FAQs or to ask a question of your own, feel free to join the discussion by [clicking here](#) or use the Facebook icon located at www.pscpartners.org .



Your Chance to Win a Complimentary Conference Registration for 2013

In past years, free conference registrations were awarded to the top two fundraisers. This year, all those who organize a fundraiser for The Road to Research will be acknowledged for their fundraising efforts at the conference banquet and will have a chance to win *one of two* free 2013 conference registrations.

Now is the time to create history. We have a great challenge for our community: Fifty new person-to-person fundraising campaigns by April 30th! Letter-writing campaigns, creative fundraisers, we are full of suggestions and would love to hear yours. This is a huge goal, but we can do it!



Please consider participating in this campaign. We need you! You can do your part to raise funds in support of our research grant program and to find better treatments and realize our greatest dream of finding a definitive cure for PSC.

Remember, it can be as simple as a yard sale, a letter-writing campaign, or just asking friends and family to join the cause.



Just say you are interested to launch your personal fundraiser, and we will walk you through the process. We are just waiting to be asked! contactus@pscpartners.org



The need is great! The time is now! Together in the fight...whatever it takes!



Fundraising Spotlight: Bek Goldsmith

by Sandi Pearlman

Most of us can remember what it's like to be healthy. I mean, it may feel like some foggy watercolored painting, but we sort of know it was once there, this life where we didn't yet know the ramifications of the initials PSC. But for Bek Goldsmith, that day isn't even a halcyon memory. There's no glimpse or fond sighs for the "good, old days" because, in Bek's case, she'd have been too young to remember them. Bek was just 5 months old when she first fell ill. Then, a few short months later, when she was just a year, she was diagnosed with the words her family will never forget: Primary Sclerosing Cholangitis.

Now 13 years old, Bek has been dealing with PSC for all of her life. Yet, despite numerous hospitalizations, problematic symptoms and what seems like an endless wait on the transplant list, she's put herself out there, making a real difference for PSCers everywhere and earning funds to get us all that much closer to better treatments and a cure. When I first received an email in my inbox from this little 10-year-old Australian girl wanting to help, I had no idea just how truly admirable she is or how much I'd come to adore her. It was just a quick note, something her mother urged her to write after Bek decided that [she] "didn't need to wait until [she] was an adult to do something useful like fundraise." Even now, Kerrie, Bek's mum, still admits surprise that her shy, little Bek took her up on her suggestion to write.

But Bek's done so much more than just write. She's now held three successful fundraisers for PSC Partners Seeking a Cure and, if rumors are true, is already thinking about ideas for her fourth. She's actively trying to make people understand that PSC isn't contagious or something they need to shy away from or hide from. It seems nothing can keep Bek down, not bleeds or hospitalizations, NG tubes or missing school. Gathering together friends and family to help when she's not strong enough to physically carry out what she wants, Bek still is a whirlwind of ideas and plans. When she took on her first fundraising endeavor, a cake stall (bake sale), the location she chose didn't give her as much foot traffic as she'd like. But not one to let that stop her, Bek picked up her stall, grabbed her friend and the two went door-to-door selling cakes. "It was hard work, but we had fun" Bek says. In fact, her words of wisdom when encouraging others to get out there and fundraise for better treatments and a cure for PSC are simple: "Just do it--it's fun. Fundraising is just fun – I like doing it and I find it hard to understand why anyone wouldn't want to help."

Last year, Bek chose Beanie Kids as her fundraiser of choice. She wasn't feeling well and enlisted her mum's help, because feeling lousy wasn't going to be a reason to quit. "I really want to find a cure for PSC so others don't have to go through what I have." She goes on "[Mum says] In part, it's about putting back into the community that gives so much, and that makes you feel good. If you have purpose in what you do in life there is much greater meaning, connectedness and happiness."

There are those that might pity Bek because of her illness. But she shows them every single day that nothing could be farther from the truth. Questions like what life with PSC has taught Bek are near impossible for her to answer because she's never known a life without it. However, she does know "being sick has helped me appreciate and value my family and friends and understand what is important in life."

And aside from fundraising and finding a cure, Bek does know what's important. It's her friends and her family, her little sister Jasmine whom she adores beyond reason and vice versa, her big brother Josh, an avid sportsman, and she's absolutely crazy in love with her pup, Lilly, a 20 month old Cavoodle. Bek has never met another PSCer face to face, but thanks to technology like Skype, e-mail and Facebook, she's been able to get to know others with PSC. An avid crafter, she's even learned origami from one of her PSC 'sisters' over the web. "I like that I have been able to meet others with PSC. I hope that one day I can come to one of the conferences and meet lots of people."

Bek Goldsmith is 13 years old. She spends more days in the hospital than at home lately. She's waiting for her lungs to clear so she can continue singing and has even made her own Make a Wish album. She's still waiting on transplant. Her mum, Kerrie, describes her as fearless. I'd agree. Bek is fearless. But she's also so much more. She's a hero, a friend, a teenager, an inspiration and, above all, very much loved by those near and far. For me, Bek, my inbox brought so much more than a fellow fundraiser or even just a friend that day. In finding you, I found the other pea in my pod and I can't wait to cheer along with you on the day that we finally find PSC is no longer a battle without a cure! Thanks for all you've done and all you do. Can't wait to see what you cook up next. Together in the fight and always by your side!



TIME	SESSION	LOCATION
FRIDAY, MAY 4, 2012		
9:00 AM - 8:00 PM	Check-in/PSC Partners Registration	DOUBLETREE
10:30 AM - 12:30 PM	Pre-Conference Event: Brunch	ROCHESTER ART CENTER
1:30 - 4:00 PM	Stress Management and Resiliency Training (SMART) Program for PSCers and Caregivers Amit Sood, MD, MSc , Associate Professor of Medicine, Director of Research and Practice, Integrative Medicine, Associate Director, General Internal Medicine Research	MAYO CLINIC GONDA BUILDING GEFFEN AUDITORIUM
5:30 - 6:00 PM	Newcomer Orientation	DOUBLETREE
6:00 - 6:30 PM	Mentor/Mentee Casual Meet & Greet	DOUBLETREE
6:30 - 9:00 PM	Registration and Welcome Dinner	DOUBLETREE BALLROOM
SATURDAY, MAY 5, 2012		
7:30 - 8:30 AM	Buffet Breakfast	DOUBLETREE BALLROOM
8:30 - 8:40 AM	General Session Opening Remarks: Don and Ricky Safer PSC Partners Seeking a Cure	DOUBLETREE BALLROOM
	SESSION I Keith D. Lindor, MD Moderator Executive Vice Provost of Health Outcomes@ASU	
8:40 - 9:00 AM	Presentation 1: Management of Symptoms Related to PSC Jayant A. Talwalkar, MD, MPH Associate Professor of Medicine, Mayo Clinic Rochester	
9:00 - 9:20 AM	Presentation 2: Coping with PSC: It's Not "All in Your Head" Philip Burke, PhD Clinical Psychologist, Assistant Professor of Clinical Psychology Southern Illinois University at Carbondale, PSC Patient	
9:20 - 9:40 AM	Presentation 3: MELD System: Past and Present Patrick S. Kamath, MD Professor of Medicine, Mayo Clinic College of Medicine	
9:40 - 10:15 AM	Questions and Answers Panel: Drs. Talwalkar, Burke and Kamath	
10:15 - 10:35 AM	BREAK WITH SNACKS	BALLROOM FOYER
	SESSION II Konstantinos N. Lazaridis, MD Moderator Associate Professor of Medicine, Associate Chair Research Division of Gastroenterology and Hepatology Associate Director – Rochester Center for Individualized Medicine Mayo Clinic College of Medicine	
10:35 - 10:55 AM	Presentation 4: Ongoing and Future Medical Therapies for PSC Keith D. Lindor, MD	
10:55 - 11:15 AM	Presentation 5: PROGRESS: Beginning to Understand the Genetic Predisposition to PSC Konstantinos N. Lazaridis, MD	
11:15 - 11:35 AM	Presentation 6: Sleep and Chronic Illness John G. Park, MD, FCCP, FAASM Assistant Professor of Medicine Division of Pulmonary Critical Care and Sleep Mayo Clinic College of Medicine	
11:35 - 12:10 PM	Questions and Answers Panel: Drs. Lindor, Lazaridis and Park	

12:10 - 1:30 PM	LUNCH	BALLROOM FOYER
12:10 - 1:30 PM	Group Lunches in Breakout Rooms Teen PSCers Female PSCers in their 20s/30s Male PSCers in their 20s/30s Female PSCers Male PSCers Post-Transplant PSCers Parents of Pediatric PSCers Parents of Adult PSCers Spouses/Caregivers of PSCers Siblings & Other Caregivers of PSCers	
BREAKOUT SESSIONS		
1:30 - 2:15 PM	SESSION I	
Cancer Surveillance: Risks and Outcomes (Repeated in Session II)	Gregory J. Gores, MD Chair of Gastroenterology and Hepatology Mayo Clinic Rochester	
Inflammatory Bowel Disease and PSC (Repeated in Session II)	Sunanda V. Kane, MD Professor of Medicine Division of Gastroenterology and Hepatology Mayo Clinic College of Medicine	
Role of MRI and Advanced Endoscopic Techniques in PSC	Jayant A. Talwalkar, MD, MPH Associate Professor of Medicine Mayo Clinic Rochester	
Living Donor Liver Transplantation: A Guide	Julie K. Heimbach, MD Surgical Director, Liver Transplantation Mayo Clinic Rochester	
Proactive Planning for Transplant	Lynn Pearson, RN, CCTC Moderator Mayo Clinic Rochester Jayne Kleist, LSW , Mayo Clinic Rochester Marilyn Salley Patient Financial Services Representative Transplant Programs, Mayo Clinic Rochester	
Pediatric Parents: Letting your Kid Be a Kid	Saul J. Karpen, MD, PhD Professor of Pediatrics, Division Chief, Pediatric Gastroenterology, Hepatology and Nutrition Emory University School of Medicine	
Special Topics for 20s/30s Female PSCers	Nataliya Razumilava, MD Fellow, Division of Gastroenterology and Hepatology Mayo Clinic Rochester Andrea A. Gossard, RN, CNP Assistant Professor of Medicine Mayo Clinic Rochester	
Special Topics for 20s/30s Male PSCers	Craig S. Lammert, MD Research Fellow in Gastroenterology and Hepatology Mayo Clinic Rochester	
Caregivers: Helping Us Help Others	Mike Pearlman, JD, PSC Parent Moderator Panel of PSC Caregivers	
2:15 - 2:35 PM	BREAK	

2:35 - 3:20 PM	SESSION II
Cancer Surveillance: Risks and Outcomes (Repeated in Session I)	Gregory J. Gores, MD Chair of Gastroenterology and Hepatology Mayo Clinic Rochester
Inflammatory Bowel Disease and PSC (Repeated in Session I)	Sunanda V. Kane, MD Professor of Medicine Division of Gastroenterology and Hepatology Mayo Clinic College of Medicine
Life After Liver Transplant	Jayant A. Talwalkar, MD, MPH Associate Professor of Medicine, Mayo Clinic Rochester
Interpreting Your Test Results	Andrea A. Gossard, RN, CNP Assistant Professor of Medicine Mayo Clinic Rochester
Teen Session: Letting Yourself be a Teenager	Saul J. Karpen, MD, PhD Professor of Pediatrics, Division Chief, Pediatric Gastroenterology, Hepatology and Nutrition Emory University School of Medicine
Gluten Free Diet and Celiac Disease	Joseph A. Murray, MD Professor of Medicine, Consultant, Division of Gastroenterology and Hepatology and Department of Immunology, Mayo Clinic Rochester Jacalyn A. See, MS, RD Clinical Dietitian, Assistant Professor of Nutrition, Mayo Clinic Rochester
Understanding PSC Medications	Christine M. Formea, Pharm D. Manager of Pharmacy Research Service, Mayo Clinic Rochester
3:20 - 3:45 PM	BREAK WITH SNACKS
3:45 - 4:30 PM	SESSION III
The Future of PSC Research	Keith D. Lindor, MD Moderator Executive Vice Provost of Health Outcomes@ASU Panelists: Konstantinos N. Lazaridis, MD Associate Professor of Medicine, Associate Chair Research Division of Gastroenterology and Hepatology Associate Director – Rochester Center for Individualized Medicine Mayo Clinic College of Medicine Jayant A. Talwalkar, MD, MPH Associate Professor of Medicine Mayo Clinic Rochester Saul J. Karpen, MD, PhD Professor of Pediatrics, Division Chief, Pediatric Gastroenterology, Hepatology and Nutrition Emory University School of Medicine
Relationships, Sexuality and Family Planning	Andrea A. Gossard, RN, CNP Assistant Professor of Medicine Mayo Clinic Rochester Sunanda V. Kane, MD Professor of Medicine Division of Gastroenterology and Hepatology Mayo Clinic College of Medicine

How Do I Deal with Life and PSC?	Philip Burke, PhD Clinical Psychologist, Assistant Professor of Clinical Psychology Southern Illinois University at Carbondale, PSC Patient Wendi M. Hirsch, PhD Clinical Psychologist, Sister of PSC Patient
Be Informed: Disability Benefits and Employment Law Issues	Rebecca Long, JD, PSC Partners Board Member, Legal Advisor Jeremy Burke, ALHC , Learning Consultant Aetna Disability Benefits Management Services Tiffany Rotondo, PHR , Corporate Human Resources Generalist The Jel Sert Company
Special Topics for Post-Transplant PSCers	Aubrey Goldstein, MD Vice-President, Medical Staff, Bruyere Continuing Care, Member of PSC Partners Scientific/Medical Advisory Committee PSC Post Transplant Patient
Make a Difference : Effective Person- to-Person Fundraising Made Easy	Ken Shepherd , Managing Partner, Miller Toyota & Warrenton Toyota PSC Parent Sandi Pearlman , 2012 Conference Co-Chair Community Relations Chair, PSC Partners Seeking a Cure PSC Patient Meegan Carey , Director of Development PSC Partners Seeking a Cure
6:00 - 9:00 PM	BANQUET DINNER
SUNDAY, MAY 6, 2012	
7:30 - 8:30 AM	Buffet Breakfast DOUBLETREE BALLROOM
8:30 - 9:15 AM	General Session PSC Partners Foundation Report Announcements Foundation Updates
9:15 - 10:15 AM	Group Sessions in Breakout Rooms Teen PSCers Female PSCers in their 20s/30s Male PSCers in their 20s/30s Female PSCers Male PSCers Post-Transplant PSCers Parents of Pediatric PSCers Parents of Adult PSCers Spouses/Caregivers of PSCers Siblings & Other Caregivers of PSCers
10:15 - 10:25 AM	Break with Snacks
10:25 - 11:20 AM	Group Sessions Reconvene GROUP BREAKOUT ROOMS
11:30 - 12:20 PM	General Session Reconvenes Feedback from Group Sessions
12:20 - 12:30 PM	Closing : Don and Ricky Safer PSC Partners Seeking a Cure

Thank you to our 2012 Conference Sponsors. Please think about joining this list of generous supporters!

Silver level sponsors

Jason and Jennifer Drasner
Steve and Joanne Grieme
Steve and Joanne Hatchett
The Pearlman Family
Ken and Patty Shepherd

Bronze level sponsors

Aubrey Goldstein and Caroline Vanneste

Conference Flyer:

Would you like to be an ambassador for PSC Partners? You can print copies and deliver flyers to your gastroenterologist or hepatologist to display in his/her office so that we can reach out more PSCers and let them know about our Mayo Clinic conference. You will find the [full-sized flyer](#) ready to print under “our Next Annual Conference” on our website (scroll down to “Miscellaneous Information.”).



**PSC PARTNERS
SEEKING A CURE**

8th Annual Conference for Patients and Caregivers In Conjunction with Mayo Clinic, Rochester MN May 4-6, 2012

The purpose of this conference is to provide a forum on the latest medical advances in the search for better treatments and a cure for primary sclerosing cholangitis and to offer PSC patients and caregivers the chance to network with speakers and fellow PSCers in an informal setting.

Featured Speakers and Topics:

- Management of Symptoms Related to PSC - **Jayant A. Talwalkar, MD, MPH**
- Coping with PSC: It's Not All in Your Head - **Philip Burke, PhD**
- MELD System: Past & Present - **Patrick S. Kamath, MD**
- Ongoing & Future Medical Therapies for PSC - **Keith D. Lindor, MD, Panel Moderator**
- PROGRESS: Beginning to Understand the Genetic Predisposition to PSC - **Konstantinos N. Lazaridis, MD**
- Sleep & Chronic Illness - **John G. Park, MD, FCCP, FAASM**
- Cancer Surveillance: Risks & Outcomes - **Gregory J. Gores, MD**
- Inflammatory Bowel Disease & PSC - **Sunanda V. Kane, MD**
- Pediatric Parents: Letting your Kid Be a Kid/Letting Yourself Be a Teenager - **Saul J. Karpen, MD, PhD**

Other Topics including:

Living Donor Liver Transplantation * Relationships, Sexuality & Family Planning * Understanding PSC Medications * Proactive Planning for Transplant * Role of MRI & Advanced Endoscopic Techniques in PSC * Sibling/PSCer/Spouse support groups.

For conference information, visit www.pscpartners.org/nextannual or write to us at contactus@pscpartners.org



**PSC PARTNERS
SEEKING A CURE**

8th Annual Conference for Patients and Caregivers In Conjunction with Mayo Clinic, Rochester MN May 4-6, 2012

The purpose of this conference is to provide a forum on the latest medical advances in the search for better treatments and a cure for primary sclerosing cholangitis and to offer PSC patients and caregivers the chance to network with speakers and fellow PSCers in an informal setting.

Featured Speakers and Topics:

- Management of Symptoms Related to PSC - **Jayant A. Talwalkar, MD, MPH**
- Coping with PSC: It's Not All in Your Head - **Philip Burke, PhD**
- MELD System: Past & Present - **Patrick S. Kamath, MD**
- Ongoing & Future Medical Therapies for PSC - **Keith D. Lindor, MD, Panel Moderator**
- PROGRESS: Beginning to Understand the Genetic Predisposition to PSC - **Konstantinos N. Lazaridis, MD**
- Sleep & Chronic Illness - **John G. Park, MD, FCCP, FAASM**
- Cancer Surveillance: Risks & Outcomes - **Gregory J. Gores, MD**
- Inflammatory Bowel Disease & PSC - **Sunanda V. Kane, MD**
- Pediatric Parents: Letting your Kid Be a Kid/Letting Yourself Be a Teenager - **Saul J. Karpen, MD, PhD**

Other Topics including:

Living Donor Liver Transplantation * Relationships, Sexuality & Family Planning * Understanding PSC Medications * Proactive Planning for Transplant * Role of MRI & Advanced Endoscopic Techniques in PSC * Sibling/PSCer/Spouse support groups.

For conference information, visit www.pscpartners.org/nextannual or write to us at contactus@pscpartners.org

Would you like to help us express our appreciation to generous donors who make the search for a cure a reality?

Here's your chance to volunteer. You can be a thank-you card writer. If you are interested, please contact us at contactus@pscpartners.org.



PSC Partners Seeking a Cure is a 501(c)3 nonprofit foundation that endeavors to find a cure for Primary Sclerosing Cholangitis.

The three-fold purpose of the **PSC Partners Seeking a Cure** foundation is to: raise funds for research on the causes and cures of PSC, provide education and support to PSC patients and their families, and promote awareness of PSC and organ donation.

Ricky Safer is the principal contact person for the PSC Partners Seeking a Cure Foundation. Reach her at: contactus@pscpartners.org

To make a tax-deductible donation, please click on www.pscpartners.org/waystodonate.

Website

www.pscpartners.org

PSC Partners Seeking a Cure Board Members

Dike Ajiri, Becky Long, Rachel Gomel, Joanne Grieme, Scott Malat, Ricky Safer, Ken Shepherd, and Deb Wente

Honorary Members

Dr. Gregory Everson, Chris Klug

Medical/Scientific Advisory Committee

Dr. Dennis Black, Dr. Christopher Bowlus, Dr. Steven Deitch, Dr. Greg Everson, Dr. Richard Green, Dr. Aubrey Goldstein, Dr. Denise Harnois, Dr. Gideon Hirshfield, Dr. Johannes Hov, Dr. Keith Lindor, Dr. Stephen Miller, Dr. Don Safer, and David Rhodes, PhD (Chair)

Note to Readers:

Articles in this newsletter have been written by persons without formal medical training. Therefore, the information in this newsletter is not intended nor implied to be a substitute for professional medical advice.

Please consult with your doctor before using any information presented here for treatment. Nothing contained in this newsletter is intended to be for medical diagnosis or treatment. The views and opinions expressed in the newsletter are not intended to endorse any product or procedure.

The Duct Newsletter

Editor: Rachel Gomel assisted by Ricky Safer

Webmaster: Arne Myrabo

Photographers: Karen Pearlman & Arne Myrabo

Contributors

Sandi Pearlman, Ricky Safer



Waiting for you in Rochester! Save the date May 4-6, 2012!

